Breath of Fresh Air

Spring 2015

Happy Spring! -Mike Fenley

Well it's getting warmer out so get out and walk for exercise. You know it's important, even if it's just a few feet. Try to increase your exercise a little each week. If you can't get out, you can exercise inside. For example, stand with knees against a chair and your hands on your hips. Inhale as you sit and exhale as you stand. Do sets of five and increase the number of sets as you can.

Meet Our Cystic Fibrosis Doctors

Dr. Allan Ramirez

Dr. Adrian O'Hagan

The U of L Adult Cystic Fibrosis program has 2 physicians with special training and expertise in cystic fibrosis.

Both of our physicians work closely with the multi-disciplinary team of health care providers providing our patients comprehensive and consistent health care based on the cystic fibrosis foundation care center standards.

Dr. Allan Ramirez joined the Cystic Fibrosis Center as the director in January 2015. You may have met him previously if you were an inpatient at Jewish Hospital. He brings experience in caring with patients who require lung transplant. He was previously at Emory University and has been at the University of Louisville for over 4 1/2 years.

Dr. Adrian O'Hagan is trained in both pediatrics and adult medicine at the Cleveland Clinic, but spends the majority of his time taking care of pediatric patients. He helps with transitioning patients from the pediatric clinic to the adult clinic. He is committed to patients and their specialized needs .

tStrides5K Walk
Louisville Slugger Field
Registration 9 a.m.

Monday,
Cure Cup Golf Classic
Audubon Country Club

F Great Strides 5K Walk
Louisville Slugger Field
Registration 9 a.m.

What is the CF Foundation

The Cystic Fibrosis Foundation (CFF) is a nonprofit donor-supported organization dedicated to research, fundraising, advocating, and educating.

The Foundation was established in 1955 with a focus of supporting the development of new drugs to battle this disease, improving the quality of life for those with the disease, and to one day find a cure.

In 1989 scientists who were supported by the CF Foundation discovered the defective gene which causes CF.

There are currently 115 care centers nationwide, including 94 adult centers, counting ours. There are more than 70 chapters and branch offices around the country that assist in fundraising and hosting special events for vital CF programs.

CF Foundation 800-344-4823

Our Featured Patient

I was born in June 1959. I always had sinus and respiratory problems but was never tested for CF. As I got older I was always told I didn't have CF because of my age. I started Nursing school in my mid 30's, and I didn't know that a productive cough with colored sputum was abnormal. Finally, after taking many different antibiotics that never changed things, the Dr. I was seeing sent me to the CF clinic. I was tested for CF and it was positive. Growing up I always got short of breath easily, at the age of 13 I started coughing up blood, and the next day I had a middle and partial right lobectomy. I was a trumpet player in middle school and 2 years in high school. After the surgery I had to quit. I had to have sinus surgery the year before, the year of, and the year after my lobectomy.

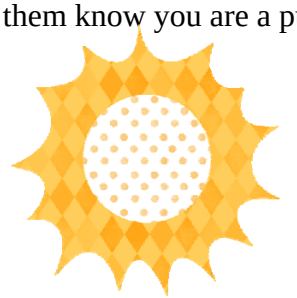
After I became a Nurse, I noticed I was getting more short of breath. In 2012, I was averaging being in the hospital on IV antibiotics 2-3 times a year. My wife and I started travel Nursing in 2011, and in Sept my CF really started getting worse. In December of 2013 I had to quit work. I was hospitalized in January of 2014 and put on oxygen, told I had to quit work, and needed a double lung transplant. My lung function was down to 18%. I got the call on June 25, 2014 and I had my double lung transplant at Jewish Hospital in Louisville. I was excited and scared. It was scary waking up with no oxygen, but exciting because I could walk and not get short of breath. The more I exercised the less short of breath I got. I was discharged from the hospital on July I appreciate 8, 2014.

I'm doing great, I don't need oxygen, I don't have shortness of breath. I am doing things I haven't done in 40 plus years. June 2015 will be my first anniversary of my double lung transplant. If it wasn't for the CF clinic and the Transplant clinic (Dr's, Nurses, etc), I would not be here. them very much. If anyone who is pre or post transplant wants to talk please email or call me anytime. If there is anyone that is a post transplant patient and is a golfer, I'm looking for a partner!! I couldn't play before, now that's exciting!! I can be reached at (270)401-1577 or mfenleyrn@live.com.

Recommendations From Mike Regarding When And Who To Call

The nurse may be reached at (502)852-1080 if you:
*Get a "cold," upper respiratory infection, increased cough, changes in mucus, or fever.
*Experience constipation or abdominal pain
*Have questions about your medications, lab results, etc.
*Need refills or authorizations. REMEMBER that we need 2-7 days to get refills due to individual insurance requirements.

*Call (502)588-4600 to speak to someone in the clinic or to a physician on call or after hours. Let them know you are a pulmonary patient.



"Life is short. Break the rules, Forgive quickly, Kiss slowly, Love truly, Laugh uncontrollably, and never ever regret anything that makes you smile. "

——-Mark Twain

Order of Therapy.

Recommended by the Cystic Fibrosis Foundation

1) Bronchodilators- Such as Albuterol, Xopenex, ProAir, Proventil, Duoneb, or Combivent.

2) Wetting Agents- Hypertonic Saline 3% or 7%.

3) Mucolytics- Pulmozyme, Denufosol, or n-Acetylcystine

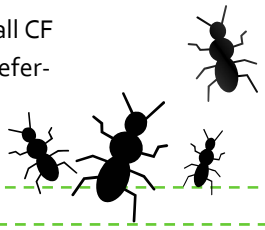
4) Airway Clearance Therapy- Vest, Acapella, Flutter, chest physical therapy, or handheld percussor.

5.) Corticosteroids- Advair, Flovent, Pulmicort, or Symbicort

6.)Antibiotics- TOBI, Tobramycin, Colistin, Gentamycin, Aztreonam, or Cayston.

New Infection Control Guidelines For People Living With Cystic Fibrosis

The CF Foundation recently updated its infection control policy in the hope of maintaining the "health and safety of people with CF wherever they gather". This applies to whether that location is in a clinic office space, at a school or CF Foundation event. The goal of this updated policy is to limit the risk of cross-infection between people with CF and is based on medical evidence that supports that all people with CF could have germs that might be spread to others with CF. The CF Foundation's 10 page document provided to all CF Centers discusses these specific recommendations and the supporting references and rationale for putting these guidelines into practice.



A summary of the specific recommendations that are a part of this document are listed below. As with all recommendations and guidelines, it is important to remember that you may not be able to prevent all infections, but you can reduce your risk.

Recommendations:

1. Only one person with CF may be present at a CF Foundation-sponsored event that is indoors.
2. At CF Foundation sponsored outdoor events, people with CF need to be 6 feet apart.
3. If there is a past or present history of a confirmed positive sputum culture for B. cepacia, this person may not attend any CF sponsored event.
4. EVERYONE (regardless of having CF or not) should clean their hands suing soap and water or an alcohol based hand gel that is at least 60% alcohol. Hands should be cleaned after coughing, sneezing, blowing the nose, before eating and after going to the rest room.
5. All people with CF should avoid any activities with other people with CF because of the risk of germ transmission. These include: shaking hands, hugging, riding in the car together, sharing hotel accommodations, exercise classes or sharing any cups or utensils.
6. Information about whether a person has CF or what germs that they have in their lungs is to be maintained as confidential unless the family wishes to have this information known.
7. Patients with CF must wear a mask in the waiting room and throughout the health facility except in their own exam room (clinic or hospital room). Infants and young toddlers may have a blanket placed gently over their face.
8. Staff in the clinic and hospital room wear will gown and gloves when seeing the patient in their exam or hospital room.
9. Schools should avoid common lunch room times, classrooms and recess times.
10. Children or adults with CF should avoid hot tubs, whirl pool tubs, and construction sites. They should also avoid cleaning stalls, pens or coops.
11. Patient exam rooms should be cleaned between patients as well as stethoscopes.
12.. People with CF who live in the same household should not share utensils, tooth brushes, or respiratory equipment. Whenever possible, they should also perform airway clearance with only one person with CF in the room at the time of treatment

We welcome Springtime ! But along with the blooming flowers, rain, and bees comes allergy season. You may find you need allergy medication, sinus rinses or nasal sprays to help get you through this season.

Patient Involvement

We would love to hear your ideas and comments. If you would like to write an article for the newsletter please call Kay Burris, R.N. at (502)852-1080, email her at kay.burris@louisville.edu or Mike Fenley. RN (retired) at (502) 365-3200 or email him at mfenleyrn@live.com. (Mike had a double lung transplant in June, 2014, you may call him with any questions.)

We are looking for patients who would either like to write an article, or be featured in the newsletter.

This newsletter will be distributed electronically for patients and families of the University of Louisville Adult Cystic Fibrosis Center.

Important Phone Numbers

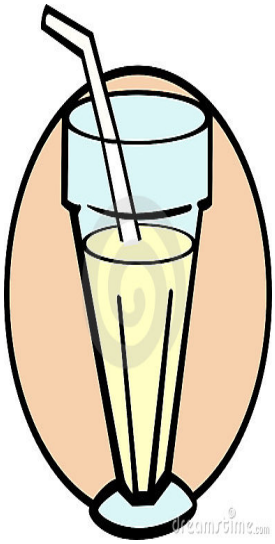
Appointment Line/Clinic (502)588-4600
After Hours/On Call Physician- (502)588-4600
Nurse Coordinator- (502)852-1080
Respiratory Therapy- (502)588-4625
Cystic Fibrosis Foundation- (800)FIGHT CF (344-4823)
Kentucky/West Virginia CFF Chapter- (502)454-8435/(800)526-8126
Cystic Fibrosis Services Pharmacy -(800)541-4959

A Respiratory Therapist's insight into ACT

Brian Mattingly, CRT is one of the respiratory therapists who work in the Respiratory Therapy Department of the Health Care Outpatient Center located in Suite 310.

He has been with the Cystic Fibrosis Center for the past four years. He performs all types of pulmonary function testing (PFTs) and patient education.

He is dedicated to his patients and is always open to questions and suggestions relating to your pulmonary health. He is able to help you with airway clearance therapy (ACT) to make sure you are getting the best outcome.



Nutrition is key to maintaining health

Five Hints to Making High Calorie/High Protein Supplements Enjoyable – (Again!)

Trying to gain or maintain your weight? Burnt out on high calorie, high protein supplement drinks? I've put together five hints for making high calorie/high protein supplements enjoyable again.

1. Be creative! Don't be afraid to "doctor" commercially prepared supplement drinks. Use flavors such as hot fudge or caramel sundae topping, peanut butter, vanilla, marshmallow topping or fruits such as orange, strawberry, banana, blueberry, or even lemon. The taste profile of these supplements will change to suit even the most finicky of palettes.

2. Switch it up! Don't get stuck in a rut. Change up the flavor, type or quantity you consume each day. Do try high calorie, high protein supplement bars as a change from drinks. You don't have to go to a specialty store to find these supplement bars. Just venture into the pharmacy section of the grocery store and you'll find meal and snack bars jammed packed with calories and protein – sometimes even more than standard commercially prepared drinks.

3. Consider smoothies and shakes from restaurants. We all know Steak and Shake and Wendy's are famous for milkshakes and Frostys ®, but don't count out Starbucks, McDonalds, Arby's and Dairy Queen to give yourself a yummy treat with a calorie boost! and Carnation Breakfast VHC ®.

4. Be your own "barista"! Use your beverage making skills at home to whip up cost effective and great tasting supplements in the comfort of your kitchen. Don't forget to use whole milk, full fat yogurt, ice cream or even heavy whipping cream or cooking oil as calorie boosters for a milkshake or smoothie. Heavy whipping cream, found in the dairy section of the grocery store, packs quite a punch at 52 calories for one tablespoon!

5. Ask me, your dietitian if you qualify for free or reduced cost nutrition supplements. While certain insurance restrictions apply, you may qualify for free high calorie/high protein supplements from your pancreatic enzyme replacement company (if pancreatic enzyme therapy is right for you). Some choices offered are Ensure Plus ®, Enlive ® and NutraShake ®. If you don't qualify for supplements via your pancreatic enzyme company, you may have nutraceutical benefits from your insurance company. Nutraceuticals (food and food related products like high calorie/high protein supplements that have medical and health benefits) are covered all or in part by certain medical insurance benefits. Your CF nurse and dietitian can help you determine if this route for receipt of high calorie/high protein supplements is right for you.

Shari R. Willy, RD, CSO, LD
Clinical Dietitian Specialist

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